

Dear Members of the Public Health Committee,

I am writing in support of HB 5326, An Act Concerning Compassionate Aid in Dying for Terminally Ill Patients. This is a highly emotional and personal issue for me and my family and I thank you in advance for taking the time to read my full testimony and take my experience into consideration as you vote on this important matter.

My father died nearly 8 years ago, just a few weeks before my wedding, from a quick and aggressive bladder cancer. We were blessed with a relatively short final stage. On Easter Sunday 2006 we gathered by his side when he stated that he was ready to stop fighting. He was dead by 3am that Thursday morning. The end came peacefully and I will be forever grateful for being with him when he took his last, quiet breath.

My mother, his bride of 48 years, was an incredibly strong widow. She carried on stoically for my five siblings and I, celebrating weddings and new grandchildren without her lifelong partner. She was living alone, a full time Director of Music at a local Catholic Church, and even chaired the National Pastoral Musicians conference held in Stamford only months after my father died. She was going strong until the fall of 2008 when her speech started to slur and her gait became unsteady. After 2 months of ruling out everything from acid reflux to a stroke, she was diagnosed on February 9, 2009 with ALS, Lou Gehrig's Disease.

Although the youngest of the six of us I took charge in managing our mom's care. Her deterioration was not to be believed. She lost complete ability to speak by March and went from needing a cane, to a walker, to push a wheelchair, to a power wheelchair, to a hospital bed in four months. We required 'round the clock live-in care starting in April. Because she couldn't speak and soon lost her ability to use function of her hands to write or type messages she was virtually a prisoner trapped in a broken body but with an impeccable mind. She was a master level, award winning bridge player and Sunday NY Times crossword puzzle finisher and sharp as a tack until the end. One of the last things she was ever able to write, though barely legible, was a note to me asking 'would you do my eulogy'. That was early August.

Because she had so many horrific experiences with caregivers who mistreated her, when her final, loving caregiver Gloria had to go on vacation for a week my mother went into Rosenthal Hospice in Stamford for a 'respite' stay as she was terrified to be in her home with anyone other than Gloria. What was supposed to be a week-long stay turned into the place she would take her last breath.

I cannot begin to express to you the horror of the 18 days that followed her arrival at hospice. If not for the incredible staff and facility of the now closed Rosenthal Hospice (an unbelievable loss to our community & state), I'm not sure we would have survived it.

My mother was able to make the decision to stop any nourishment through her feeding tube (that had been placed early on in her illness as choking on food becomes a concern when the muscles used to swallow stop working). A few days later she lost control of the last physical ability she had, the use of her eyelids to blink 'yes' or 'no' responses. As my mother's health care proxy I was forced into a situation where I had to make decisions for her. She had asked not to be drugged as the only thing she had left was her mind. But imagine what it was like for me sitting next to her as she groaned in agony and pleaded with her eyes for something I could not understand. I am still haunted by her eyes locking with mine and the memory of me only being able to say how sorry I was that I didn't know what she wanted or what we could do to make her more comfortable. I could no longer even play the game of 20 questions where she would blink responses to things like 'Are you in pain?', 'Is it the left side?', 'Right side', and on and on. I made the difficult decision to administer around the clock morphine to keep her comfortable as we literally had no way of knowing if she was in pain. In her weakened condition and without nourishment I presumed we only had a matter of days. I called my brother in England to come as I was sure she wouldn't survive Labor Day weekend.

To my horror and the emotional torture of my entire family, my mother did not succumb until September 18th. I watched while slowly her limbs turned black from lack of oxygen. We paid her beloved caregiver Gloria to come stay by her side even though there was plenty of staffing at the facility, just so my mother could take some comfort in her presence & care. I took a leave of absence from my job and called in extra support to help care for my 14 month old daughter so I could be at her bedside every minute that I possibly could. I had so many thoughts during those 2 ½ weeks of how incredibly inhumane and cruel her final journey was. She had been the most wonderful, supportive, caring, kind, generous, funny, smart, and talented woman and she deserved better. She attended daily mass and had a strong belief in God. But if she were alive today she would no doubt be supporting this bill. Her suffering was nothing short of criminal when we have the ability to assist the inevitable and end undue pain. She had prayed that the end would come quickly for her and it was a prayer left unanswered.

There is precedent with legislation like this that it can be used conservatively and appropriately. Please don't allow the fear of being labeled 'anti-life' to sway your decision. It is just the opposite. It is pro-humane and respectful of lives well led that deserve compassion, care, and dignity at the end. Please put yourself in my shoes with the person you love the most suffering intolerably and ask yourself whether you would want the option to assist them in the end. The only thing harder than losing someone you love is watching them suffer. Those words have seen me through the deaths of both my parents. I only wish I could have prevented the terrible suffering to begin with. You have the ability to give that option to other families who will be in my shoes.

Thank you.

Respectfully,

Jennifer Donalds Barahona, LCSW
74 Cardinal Street
Fairfield, CT 06825
Jennifer.d.barahona@gmail.com